"Getting Started"

Information for Parents of Infants and Toddlers Who are Deaf or Have a Hearing Loss

Massachusetts Department of Public Health, Early Intervention Services Massachusetts Commission for the Deaf and Hard of Hearing

My infant or toddler is deaf or has a hearing loss. What do I do now?

If you have just learned that your infant or toddler is deaf or has a hearing loss, you may have many different feelings and may be unsure where to turn. You may be wondering what the future will bring, and wishing that there was some help for you and your child.

Special services ARE available for you, your family and your child. Seeking information and finding special services for you and your child should be done as soon as possible. This is very important so that your child can get the right start in developing language. This short "Getting Started" guide will give you some information to start you out and some people to contact.

What does it mean to "get the right start in developing language?"

Most of us don't think much about language or how we learn it or why it is so important in life. All children need the opportunity to develop language as early in life as possible. For most children, it is a natural part of development, like walking, playing with toys and making new friends.

- Babies and young children who hear, develop speech and language naturally, simply by listening
 to people talking. They are especially interested in the sounds of the human voice and respond
 when people talk to them. They learn the language of the home and family whether it is
 Japanese, Spanish, Icelandic, English, or whatever the spoken language. They quickly begin to
 use that spoken language to learn things and to communicate with others.
- Similarly, young children whose families use American Sign Language in the home learn American Sign Language naturally by watching instead of listening.
- In situations in which two languages are used and the child can actually receive both languages, the child will learn both languages. A bilingual child might, for example communicate in both French and English, German and Icelandic, or American Sign Language and English.

Children will generally learn the language which is used in their environment, assuming that they can actually receive the language clearly through the ear, eye or a combination of both.

As a parent of family member of a child who is deaf or has a hearing loss, it will become very important to start thinking more about language. Hearing loss may interfere with the natural development of language unless steps are taken to enable the child to move forward to develop language. The really important thing with babies who are deaf or hard of hearing is to provide them with access to language. It is the job of certain professionals and others to help your child develop language, and parents have options for various types of services.

Are there many children with a hearing loss or am I alone in this?

You are not alone. There are many children who have a hearing loss and many who are deaf. Actually, approximately one child out of a thousand is born deaf. And 90% of these children have parents who hear; about 10% have parents who are deaf themselves.

There are many different causes of hearing loss in infants and toddlers, such as illnesses during pregnancy, viruses, accidents, genetic differences and heredity. And sometimes the cause is unknown.

There is assistance to help you connect with other parents if you would like to do that.

What should I do now that I know that my child is deaf or has a hearing loss?

Most parents have had no personal experience with hearing loss, so it is helpful to connect with people who can help you learn what you need to know.

- Parents generally find that it is helpful to talk with other parents who have children who are deaf or hard of hearing.
- Talking with professionals about available programs, services, and technology is generally helpful.
- It is helpful to meet other children, teenagers, and adults who are deaf or hard of hearing and discover that they are doing just fine in life and have the same range of differences among themselves as do people who hear.

It is important for parents to get clear and unbiased information on the different approaches to language development used with children who are deaf or have a hearing loss, so that they can make informed choices about what approach to choose for their child.

Meanwhile, your child is NOT a total mystery. Your child is just a child who is able to love you and be loved, play and communicate with you right now. Just use your smiles, your hugs, your playing, your facial expressions, your looking at each other, your looking at things together, and your playing together.

So, what to do? Who can help and how?

Contact MCDHH – the Massachusetts Commission for the Deaf and Hard of Hearing MCDHH can provide you with:

- Information about specialized programs and services for youngsters who are deaf or have a hearing loss and their parents and families
- Clear information about the different educational approaches to language learning and where to see these approaches in action
- Advocacy for getting proper services
- Referral to educational diagnosticians, psychologists, and other professionals who specialize in services for deaf and hard of hearing children
- Contact with other parents of children who are deaf or have a hearing loss
- Contact with adults who are deaf or hard of hearing
- Assistance in finding related services which you might need

MCDHH is a central information, referral and direct service agency in the state for Deaf, oral deaf, late deafened, and hard of hearing individuals of all ages and their families and service providers, MCDHH provides services to parents and families statewide.

Call for information and make an appointment to talk with an MCDHH Children's Case Manager at: 800-882-1155 (voice) 800-530-7570 (TTY)

CONTACT AN EARLY INTERVENTION PROGRAM:

An Early Intervention Program provides services to children, birth to three, and their families including those who have autism/PDD. These services may include:

- * special assessments that might be needed
- * developing a plan for Early Intervention services (an Individual Family Service Plan)
- * individual parent education
- * individual counseling and support for family members
- * parent groups where parents can learn from each other
- * specialized teaching for infants and toddlers including home visits and toddler groups,
- * assistance in planning for preschool

In providing services, Early Intervention Programs work in collaboration with a statewide network of specialized consultants and specialized programs for infants and toddlers who are deaf and hard of hearing and their families.

To find the Early Intervention Program in your community call:

1-800-905-8437 (voice) or 617- 624-5992 (TTY)

WHAT ARE THE COSTS?

Early Intervention services are provided at no direct cost to the family. They are paid for by the Massachusetts Department of Public Health, MassHealth, Massachusetts health insurance companies and health maintenance organizations (HMOs).

What is meant by "different educational approaches to language learning?"

Young children who hear generally develop speech and language naturally, without any conscious effort. Deaf youngsters whose parents are deaf and use American Sign Language (ASL) as the language of the home also develop the language (ASL) naturally and without conscious effort. The necessary ingredient for language development, whether it is spoken or a visual language such as ASL, is for the child to be able to actually receive (take in) the language of the environment. Currently, there are various approaches for enabling young children who are deaf or have a hearing loss to develop a first language. All children need a first language for thinking, learning, communicating, and developing relationships with parents, family, and others.

Approaches with young children who have a hearing loss are:

- American Sign Language/English bilingual approach
- English-only approaches:
 - -auditory-verbal approach
 - -auditory-oral approach
 - -cued speech
- Spoken English combined with a Manually Coded English Sign System known as Simultaneous Communication, sometimes referred to as "TC"/Total Communication

Teachers, programs and schools throughout the state use different approaches. Each approach can claim positive impact on the lives of many deaf and hard of hearing individuals. Some children have progressed very slowly or not at all through one approach, and, with a change in approach, have learned very well. There is no one "right" method for all children who are deaf or hard of hearing.

You as a parent will need information on the various approaches in order to make a choice for your child and family. Parents can be assisted in gathering objective information on all approaches from the MCDHH, other professionals, visiting a variety of programs, talking with a variety of parents, and meeting adults who are deaf and severely hard of hearing.

What are "sensory aids" for children who are deaf or have a hearing loss?

Your audiologist may recommend and/or discuss with you a sensory aid or aids for your child. Sensory aids include the following:

Hearing aids

Cochlear implants

FM systems

Sensory aids are designed to maximize available hearing primarily to assist the development and understanding of spoken language. Sensory aids are assistive technology that may be helpful, depending upon the individual child and the educational approach of choice. The assistive technology does not "cure" the hearing loss and the child who uses assistive technology will usually still need special services and programs.

Are there different types and degrees of hearing loss and does that make a difference?

Yes, there are several types of hearing loss (conductive, sensorineural, mixed, and central) and different degrees of hearing loss (mild, moderate, severe, profound, and total). The degree and type of loss have some relationship to whether:

- Medical treatment may help
- Hearing or vision or a combination of both are useful for receiving communication
- Sensory aids might enable some use of sound

The audiologist, the MCDHH case manager, and some other professionals will be able to provide you with more information on types and degrees of hearing loss.

What professionals are available to help me?

You will be working with a number of different professional people with different training and roles. Here are some of them:

Otolaryngologist (ORL) is a physician who:

- -specializes in ear, nose, throat (ENT) conditions
- -provides clearance for fitting of hearing aids
- -treats children with persistent middle ear problems
- -may provide other medical or surgical intervention or treatment

Audiologist is trained to:

- -diagnose hearing loss
- -evaluate hearing levels and abilities
- -recommend hearing aids and/or other listening devices as needed
- -fit a person with a sensory aid

MCDHH Children's Specialist is trained to:

- -provide objective information on the education of infants and children who are deaf or hard of hearing to assist parents in making a choice of communication and educational approaches
- -provide personal counseling
- -provide information and referral to other services, programs, and related resources in the state
- -connect parents with other families and with adults who are deaf and hard of hearing
- Teacher of the Deaf is trained to teach children who are deaf or hard of hearing, specializing in one or more of a variety of approaches.
- American Sign Language (ASL) Instructor, whose native language may be ASL, is trained to teach American Sign Language.
- Speech/Language Pathologist is trained to evaluate and promote speech and language development. Some have specialized training and experience in working with children who are deaf or hard of hearing.
- Auditory/Verbal Therapist is trained to promote spoken language primarily through the use of amplified residual hearing or cochlear implants.

What will my son or daughter who is deaf or hard of hearing be when he or she grows up?

Focus on being with your little child NOW. Love, share, learn to communicate and enjoy each other. When you were a child, did anyone know what YOU would be as an adult?

But we CAN say that deaf individuals are everywhere and doing nearly everything. They are:

Deaf interpreters physicians project directors

transport workers in hospitals dentists university presidents

construction workers coal miners movie stars mental health workers chemists teachers

professional athletes lawyers food service workers owners/managers of businesses accountants rehabilitation counselors computer systems operators carpenters financial consultants

The range of differences among hearing people is also present among deaf and hard of hearing people. Some are tri-lingual, have Ph.Ds, high school diplomas, college degrees, or dropped out of schools. Some marry deaf partners; some marry hearing partners. Some have children; some don't. The important thing is to work with others now to enable your child to develop language just as fast as possible.

So contact us and let's "Get Started" together!

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH):

800-882-1155 (voice) 800-530-7570 (TTY) 617-695-7500 (voice) 617-695-7600 (TTY)

Early Intervention Programs: 800-905-8437 (voice) 617-624-5070 (voice)

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